### Cognitive Interviewing Evaluation of the Pregnancy Risk Assessment Monitoring System (PRAMS) Phase 8 Supplemental Questions

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#### Introduction

This report documents findings from a cognitive interview study done by the Coordinating Center for Questionnaire Evaluation and Research at the National Center for Health Statistics, for the Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. The purpose of the study, which took place between February and March of 2016, was to examine the interpretive and cognitive processes used by respondents when answering a subset of items on the Pregnancy Risk Assessment Monitoring System (PRAMS) questionnaire, Phase 8. The PRAMS survey overall contains items related to maternal and child health, such as health care delivery (including prenatal care), health insurance, and health conditions related to pregnancy; however, this study examined questions on only three supplemental topics: family history of breast and ovarian cancer, marijuana and other drug use before, during, and after pregnancy, and environmental exposures before and during pregnancy.

#### Methods

The aim of this cognitive interview study was to explore the ways in which respondents interpreted each item on the PRAMS supplement and how they formulated a response based on that interpretation. As such, the data produced from the cognitive interviews provided in-depth understanding of the ways in which a question operated and the kind of phenomena that it captured. A total of 40 cognitive interviews were conducted with new mothers, age 18 and over, who had an infant between the ages of two and 18 months.<sup>1</sup> Twenty interviews were conducted in English and 20 in Spanish. PRAMS is designed to be primarily a self-administered, mail paper-and-pencil (PAPI) survey. However, interviews may occasionally be conducted over the phone by an interviewer. To simulate the difference in mode, some cognitive interviews were administered as a PAPI/self-administered survey and some were interviewer administered using a modified phone version of the questionnaire. Fifteen interviews were conducted with the phone version and 25 were conducted with the self-administered version of the questionnaire. Interviews conducted in English were held in the lab at NCHS; those in Spanish were conducted in the Chicago area in respondents' homes. Interviews were no longer than one hour in length. Interviewers first administered the questions or allowed the respondents to complete the questionnaire (depending on the version being used), then followed up with probes to examine the question-response process.

<sup>&</sup>lt;sup>1</sup> The PRAMS survey population includes women with children between two and 12 months. The age range was expanded in this study in order to assist with the recruitment of respondents who used marijuana during pregnancy, which proved to be challenging.

Respondents were recruited through newspaper advertisements, Craig's List, posted flyers and word-of-mouth. Recruitment was guided by the topics included in the survey questions. Therefore, women who had a family history of breast or ovarian cancer and women who used marijuana or other non-prescription drugs before, during, or after pregnancy were specifically targeted. Recruitment of women who had used marijuana and non-prescription drugs during pregnancy proved difficult, particularly among the Spanish speaking population. As a result, criteria for study inclusion was expanded to women with children between the ages of two and 18 months (opposed to the PRAMS survey criteria of two to 12 months). This strategy helped among the English language respondents, but Spanish language respondents who used marijuana during pregnancy still could not be identified.

Table 1 summarizes the demographic composition of the sample by language. Generally, the age of the English language respondents was relatively evenly spread between those under 30, those in their 30s, and those 40 and over. The Spanish language respondents were younger, most (60%) were in their 30s and only one was 40 or over. Both set of respondents tended to have a high school diploma or less, but this pattern was more pronounced among the Spanish language respondents. While 55% of the English language respondents had a high school diploma or less, 85% of the Spanish language respondents fell into this category.

**Table 1: Sample Summary by Language (n = 40)** 

	English Language (n = 20)		Spanish Language (n = 20)	
	Number	Percent	Number	Percent
Age				
Under 30	9	45%	7	35%
30-39 Years	7	35%	12	60%
40 and Over	4	20%	1	5%
Race/Ethnicity				
Non-Hispanic White	4	20%	0	0
Non-Hispanic Black	10	50%	0	0
Hispanic	5	25%	20	100%
Asian	1	5%	0	0
Education				
High School Diploma or Less	11	55%	17	85%
2 or 4 Year College Degree	7	35%	3	15%
Graduate Degree	2	10%	0	0

#### Method of Analysis

Analysis of the interviews included a three-stage process conducted with Q-Notes, a data entry and analysis software application. Q-Notes ensured a systematic and transparent analysis across all cognitive interviews and provided an audit trail depicting the way in which findings were generated from the raw interview data. Original interview text from every interview was first summarized into detailed interview notes. Summary notes specified the way in which individual respondents answered every survey question, including each respondent's interpretation of questions and key terms, activities and experiences considered by respondents, and any response difficulties and errors.

Next, analysis was conducted systematically across interviews, identifying interpretive patterns (including patterns of response errors) and developing larger conceptual themes. Findings from this second level of analysis show the concepts captured by the questions. Finally, a third level of analysis was conducted across subgroups of respondents to determine whether patterns tended to vary by group. Quotes from individual interviews are presented and used as examples of the themes that have been developed by examining all data points.

A general overview of key findings is described next, followed by a question-by-question analysis of all items in the questionnaire.

#### **Summary of Key Findings**

Timeframes and Intended (or Planned) Pregnancies

Many respondents made mistakes with the timeframes. For example, question 27 asked about a variety of drugs taken the month before pregnancy. This was the only question which used that timeframe. Some respondents kept the timeframe in mind, but many did not. Many respondents ended up answering based on what they took *during* their pregnancy; some thought of the 12 months before pregnancy.

Timeframe issues were sometimes exacerbated on the basis of whether or not a respondent had intended to get pregnant. This pattern was evident among questions asking about the first three months of pregnancy and occurred predominantly among English language respondents. Respondents who did not intend their most recent pregnancy would often provide answers on the basis of what they did *once they discovered they were pregnant*. However, this discovery was often made between one month and three months into pregnancy. One respondent was 5.5 months pregnant when she found out. Questions 12b, 14, and 23b all had false negative response errors from women who were not intending their most recent pregnancy. For example, question 14 asked how often a respondent used marijuana during the first three months of pregnancy. Many women with unintended pregnancies reported, 'I did not use marijuana' during the first 3 months of pregnancy when, in fact, they had. Their rationale was that they stopped smoking it once they discovered they were pregnant. The important factor in interpreting the intent of the question rested on the notion that they made a conscious decision to use marijuana while pregnant.

#### Lack of Knowledge

Many respondents lacked the knowledge necessary to adequately answer some of the questions. For example, question 45 asked how often respondents did a variety of things during their most recent pregnancy, including eating fish with high levels of mercury and drinking out of plastic bottles made with BPA. Many respondents did not know which fish contain mercury and many did not know whether bottled drinks (like spring water or juice) have BPA. Similarly, question 39 asked about whether respondents used BPA-free baby bottles. Even though there was a 'don't know' category, some respondents gave a different answer when in fact they did not know. For example, some answered 'yes, all the time', assuming that all new bottles are BPA-free.

In addition, several questions asked about a respondent's residence. Many respondents, especially Spanish language respondents, had limited knowledge of their residence because they lived in rented apartments or houses. For example, question 40 asked if their home was built before 1978. Many

respondents did not know and felt unable to even estimate the age of the building. As a result, in the self-administered mode, they left the question blank or wrote 'don't know' to the side. Similarly, question 42 asked whether their home had a carbon monoxide detector. Many respondents did not know but were not given a 'don't know' option. As a result, they either left the item blank or guessed.

Finally, many respondents had little or no knowledge of their family health history. Sometimes this was because they simply did not have close relationships with their family members. Other times they did not know one side of the family (due to being raised by one parent) or were adopted. Respondents with these experiences had different ways of approaching the questions. Some respondents would leave them blank or answer 'don't know' (often writing in the margin) while others would answer 'no'. When 'no' is a proxy response for 'don't know', analysts may mistakenly interpret these estimates. A preamble of 'to the best of your knowledge' may be helpful in bringing a consistent interpretation to an answer of 'no' and may minimize missing data.

#### Interpretation of Key Terms or Phrases

#### 1. Definition of "use" or "have contact with"

Some questions in the section on environmental exposures asked respondents whether they 'used' or 'had contact with' certain products or items during pregnancy. Respondents had different ideas about what that meant in terms of question intent. Some interpreted the concept more broadly as being exposed to chemicals in the items or products asked about. Others had a more narrow interpretation and thought specifically of handling the items or products. Respondents who interpreted these questions as trying to measure exposure to these chemicals during pregnancy tended to answer 'yes', even if they, themselves, did not handle or apply the item. For example, question 36 asked if respondents used weed killer (among other things) one or more times a week during pregnancy. Some were not sure if someone else spraying chemicals on their lawn should be reported as a 'yes'. They, themselves, did not apply the chemical, but they did have exposure to it by simply being in their yard after the application. However, not all respondents understood the questions as asking about exposure more generally. Some had a literal interpretation, and reported 'no' if they did not directly handle or work with a product themselves. For example, question 37 asked if respondents used or had contact with a variety of items on a daily basis during pregnancy, including freshly dry cleaned clothes. Some respondents answered 'no' to using freshly dry cleaned clothes (even if they wore them or handled them) because they did not, themselves, dry clean the clothes. For example, one respondent answered 'no', even though she worked during part of the pregnancy at a dry cleaning store handing the clothes to customers, because she never wore dry cleaned clothes nor did she dry clean them herself.

#### 2. "Talk with you": An Actual Conversation or Any Conveyance of Information?

Questions 22 and 44 asked whether a clinician talked with respondents about a variety of topics during any prenatal care visit. Some respondents did not think specifically of any conversation, but simply remembered being presented with educational material (such as pamphlets or videos). Relatedly, some reported 'yes' even when the conversation did not take place during the most recent pregnancy, did not take place during a prenatal care visit, or took place because it was the respondent – not the provider – who initiated the conversation. In essence, these questions were interpreted as either asking whether doctors had discussions with respondents about certain topics or whether the information was conveyed at all (regardless of when, where, or how). The latter interpretation centers more around the idea that the

question was asking whether the respondent had the knowledge being asked about (for example, knowing that it is not safe to use pesticides during pregnancy), not whether physicians covered these topics during prenatal care visits. At root, the perceived unit of analysis in the question can be interpreted as either the clinician (what did the clinician do?) or the respondent (what do you know?).

#### Social Desirability

While most respondents did discuss marijuana use in the interviews, some were reluctant, and almost no one admitted to taking any 'stronger' illegal drugs such as cocaine or heroin. There was some evidence that social desirability was present, especially among the English language respondents. For example, one person was very offended by the line of inquiry and suggested that the questions assume a person is using drugs. Another respondent was screened into the study based on her answer that she had smoked marijuana, but during the interview insisted that she had never done marijuana in her life. Another respondent gave conflicting accounts, answering 'did not use marijuana' to question 14, and 'no' to 23b, but admitting during probing that she smoked marijuana when she found out she was pregnant because she was very stressed about it (she had not planned to get pregnant). Finally, another respondent answered '1 day a week or less' in question 13 but during probing admitted that she didn't like that category because it made her sound like a 'pot head' because one day a week is frequent in her mind (she smoked 'maybe once a month').

#### Mode

In the self-administered version, respondents made mistakes in following skip pattern instructions. The tendency was for respondents to answer questions they should have skipped rather than skipping questions they should have answered.

In the phone version, the longer questions – especially those with many prescription drug names – were very cumbersome and difficult to read. For example, interviewers frequently struggled pronouncing the names of various drugs and respondents could not keep all elements of some questions in mind. This was especially evident in questions 28 through 31.

#### **Question-by-Question Analysis**

This section lists all items in the questionnaire and discusses the findings associated with each.

The first questions are about your family history of breast and ovarian cancer.

1. Have any of your close family members who are related to you by blood (parents, full sisters or brothers) had breast OR ovarian cancer?

П	N	lO

□ Yes

Answer	Cases

No	27
Yes	12

<u>Findings</u>: Because the introductory statement specifies the type of cancer being asked about, respondents correctly answered in relation to only breast and ovarian cancer. However, several other difficulties arose for respondents: their level of knowledge about family history and the family members about whom they were thinking (nuclear vs. extended family).

First, during probing many respondents said they did not have full knowledge of their family history of cancer or other health conditions. Sometimes this was because those things simply are not discussed in great detail among family members. For example, one respondent reported 'yes' thinking of her mother. However, it was unclear to the respondent whether her mother actually had breast cancer because her mother did not communicate much detail to the respondent. She said,

My Mom...I think they detected it on one of her breasts. But she went to the doctor or the hospital and they helped her. I don't know if it was something...how do you say...that it was not so cancerous. They were able to detect it and with medications and treatment she does not have it anymore. She doesn't talk about it much.

Another reason respondents do not have adequate knowledge is because they do not know all members of their family. One respondent who was adopted left the question blank. Other respondents were raised by only one parent and knew nothing about the other parent's history. These respondents tended to answer 'no'. For example, one respondent said, "I grew up with just my Dad, so I don't know my Mom's history. So I was pretty much considering his side of the family." She answered 'no' to the question. In several instances, respondents with only partial knowledge of their family chose to answer 'no' as a proxy response for 'don't know'. For the most part they intuited that the question was asking 'to the best of your knowledge.'

A second difficulty that sometimes resulted in response error was created by the word 'close'. Several respondents answered 'yes' to the question but during probing revealed that they were thinking about extended family members in addition to their nuclear family (or family of orientation). When they answered the question, they were thinking about family members to whom they are emotionally close and did not see the parenthetical examples offered by the question. For example, when asked to explain her answer of 'yes', one respondent said, "My grandmother had ovarian cancer." Several others were also thinking of grandmothers and a couple others also thought of aunts and cousins. One Spanish language respondent answered 'yes' to the question and explained, "One of my cousins had breast cancer...she lasted like 10 years with the cancer." It seems that rather than reading the entire question, respondents sometimes focused on the word 'close'. This was especially (but not exclusively) true of the Spanish language respondents. For example, one Spanish language respondent did answer correctly (no) but was nevertheless thinking of extended family. When asked about whom she was thinking, she said, "Relatives like my parents, my aunts and uncles on my Mom's side or my Dad's side." Similarly, another Spanish language respondent answered 'no' and said the question was asking "If any of my family members has had breast cancer. Aunts...or men too...grandparents. But none of them have had breast cancer"

Translation Note: There was an issue in questions 1 through 5 in Spanish testing with the term 'blood relative'. 'Relación consanguínea' was not understood by all respondents as intended. One recommendation is to instead use 'relación consanguínea o de sangre'.

- 2. Has any woman in your family who is related to you by blood (grandmother, aunts, cousins, mother, sisters) had breast cancer before age 50?
- □ No
- □ Yes

Answer	Cases
No	26
Yes	13

<u>Findings</u>: Most respondents were thinking about all family members in this question, largely because they were thinking of all family members in the previous question as well. No response error was found. However, one respondent who was (correctly) thinking of immediate family members in the previous question, also thought about those same members in this question. She said, "The first one was 'no', that's why I answered the second one 'no'. Because it was a cousin." To her the distinction between the two questions was the "before 50" age range.

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- 3. Has any woman in your family who is related to you by blood (grandmother, aunts, cousins, mother, sisters) had breast AND ovarian cancer?
- $\; \square \; No$
- □ Yes

Answer	Cases
No	35
Yes	4

<u>Findings</u>: Most respondents were not confused and answered this question thinking about all family members. However, two possible problems exist. First, respondents may not read that the question is about two types of cancers. One respondent reported a false positive because she was answering only for breast cancer. Second, respondents may think of multiple family members when answering the question. One respondent gave a false positive answer because her grandmother died of ovarian cancer

and an aunt died of breast cancer. She was essentially answering question number six (Do you have 2 or more relatives with breast and/or ovarian cancer?).

Translation Note: There was an issue in questions 1 through 5 in Spanish testing with the term 'blood relative'. 'Relación consanguínea' was not understood by all respondents as intended. One recommendation is to instead use 'relación consanguínea o de sangre'.

4. Has any man in your family who is related to you by blood (grandfather, uncles, cousins, father or brothers) had breast cancer?

 $\square$  No

□ Yes

Answer	Cases
No	39
Yes	0

<u>Findings</u>: While some respondents expressed surprise that a man could have breast cancer, they understood that the question was asking about male family members. One person remarked, "Men also get breast cancer? I have never heard that men would also get breast cancer." All respondents answered 'no'. Lack of knowledge was the only possible difficulty associated with this question. One respondent checked off 'no' but wrote "not sure" in the margin. When asked about it she said, "You don't always know the family history."

Translation Note: There was an issue in questions 1 through 5 in Spanish testing with the term 'blood relative'. 'Relación consanguínea' was not understood by all respondents as intended. One recommendation is to instead use 'relación consanguínea o de sangre'.

5. Have any of your family members related to you by blood (grandparents, aunts, uncles, cousins, parents, sisters, or brothers) had bilateral breast cancer (breast cancer on both sides)?

□ No

□ Yes

□ I don't know

Answer	Cases
No	31
Yes	2
I don't know	5

<u>Findings</u>: Unlike the previous questions, 'I don't know' was included as an option in this question and five respondents chose it. This is because they often lacked complete knowledge about family members' health. For example, one respondent who chose 'don't know' explained, "I don't know if the one aunt on my Dad's side who had it before she was 50...if it was on both or one. I'm trying to think. I want to say 'yes, on both', but I really don't know." Incomplete knowledge was had by respondents even for close family members. Another person said, "My mom passed. And my Dad doesn't share that much, so I don't know."

Additionally, most respondents did not know the meaning of "bilateral breast cancer" and relied on the parenthetical explanation to understand the question. The term "bilateral breast cancer" might be unnecessary for the question to adequately convey intent.

Translation Note: There was an issue in questions 1 through 5 in Spanish testing with the term 'blood relative'. 'Relación consanguínea' was not understood by all respondents as intended. One recommendation is to instead use 'relación consanguínea o de sangre'.

### 6. Do you have 2 or more relatives with breast and/or ovarian cancer?

□ No

□ Yes

Answer	Cases
No	33
Yes	6

<u>Findings</u>: This question posed no difficulty for all but one respondent. The present tense of "have" caused one respondent to clarify that she was thinking only of relatives who are alive.

### 7. Have you ever received genetic counseling for cancer risk?

□ No

□ Yes

Answer	Cases
No	22
Yes	1

<u>Findings</u>: Several respondents who should have skipped this question answered it by mistake. This was a general pattern in the self-administered version. Respondents often missed skip instructions and answered questions they should have skipped. All but one respondent answered 'no' to the question.

One source of confusion was the term 'genetic counseling'. While many respondents intuited correctly based on the question context, several respondents came to incorrect conclusions about what it meant. Some thought it was referring to cancer screening procedures. For example, one respondent answered 'no' but said, "They say after you hit 40 that I should probably go and get tested for it because it runs in the family. Breast and ovarian cancer – they usually put those side-by-side." When asked to explain, the respondent was actually thinking about mammograms and Pap tests. Another respondent thought it referred to genetic testing of the fetus. When asked what the purpose of genetic counseling was, she said, "To tell me about conditions that he [the baby] could possibly have."

Several of the Spanish language respondents saw the word 'counseling' and were prompted to think of emotional or health counseling. One respondent said, "Since my Mom more or less had cancer, I could – as her daughter – go to get counseling to learn more or less what cancer is like and those things." Another person said, "Like they teach us about cancer and give us instructions about how we should...they orient us what cancer is like and how to help a person who has that disease." One respondent ended up correctly piecing it together and said it was "Some type of help or support for any disease like cancer. I don't know. Something genetic...like if I could inherit breast cancer from my aunt or someone in my family." Even though all answered 'no' with no response error, it was clear that many did not easily understand what the question was asking.

### 8. What was the MAIN reason you had genetic counseling?

- □ My doctor recommended it
- □ I requested it
- $\hfill \square$  A family member suggested it
- □ I heard or read about it in the news
- □ Other Please tell us:

Answer	Cases
My doctor recommended it	1
I requested it	0
A family member suggested it	0
I heard or read about it in the news	0
Other> Please tell us:	0

<u>Findings</u>: This question was not adequately tested because only one respondent reported ever having genetic counseling. However, it should be noted that she checked more than one response ('Dr recommended it' and 'family member suggested it') because she did not see that the question was asking about her *main* reason.

# 9. Thinking about your MOST RECENT genetic counseling session for cancer risk, what kind of cancer was it for?

- □ Breast cancer
- □ Ovarian cancer
- □ Other Please tell us:

Answer	Cases
Breast cancer	1
Ovarian cancer	0
Other> Please tell us:	0

<u>Findings</u>: This question was not adequately tested because only one respondent reported ever having genetic counseling.

#### 10. Do you have Ashkenazi Jewish heritage?

- □ No
- □ Yes
- □ I don't know

Answer	Cases
No	33
Yes	0
I don't know	5

<u>Findings</u>: Respondents answered either 'no' or, to a less extent, 'I don't know' to this question. Oftentimes those two responses meant the same thing because no one understood the term 'Ashkenazi'. One respondent left it blank saying, "I'm not sure what that is." Another respondent said, "Is that a place? I did not understand that." Many respondents answered 'no' as a proxy for 'don't know'. The most common rationale for this response pattern is explained by one respondent who said, "I don't know what that is, so I must not have it." The Spanish language respondents were much more likely to answer 'I don't know' over 'no' when they did not understand the term. To them, the response option 'I don't know' meant that they did not know what Ashkenazi was – not necessarily that they did not know what their cultural/ethnic background was. No English language respondents answered 'I don't know'.

The next questions are about marijuana and hashish. Marijuana is also called pot or grass. Marijuana is usually smoked, either in cigarettes, called joints, or in a pipe. It is sometimes cooked in food. Hashish is a form of marijuana that is also called "hash." It is usually smoked in a pipe. Another form of hashish is hash oil.

<u>Findings</u>: The introduction to the section on marijuana and other drug use was unnecessarily long. In the phone version it was very cumbersome to read and in the self-administered version there was little evidence that respondents read the entire script. Moreover, there was no evidence to suggest that respondents even needed that much information. All knew and understood what marijuana is; therefore, a more concise introduction (consisting of, perhaps, only the first sentence) would be sufficient.

### 11. Have you ever, even once, used marijuana or hashish?

□ No

⊓ Yes

Answer	Cases
No	24
Yes	15

<u>Findings</u>: All respondents understood this question and no response error was found. Respondents understood that it was asking not only about current or regular use, but also infrequent or single event use. For example, one respondent said the question was asking about "Even if it's just a puff, like at school or something like that." As a result, the question captured both regular smokers and those who had tried marijuana only once. Knowledge of hashish was the only issue with this question. All respondents knew what marijuana was, but some had not heard of hashish, particularly among the Spanish language respondents.

# 12. During any of the following time periods, did you use marijuana or hash in any form? For each time period, check No if you did not use then, or Yes if you did.

	NO	res
a. During the 12 months before I got		
pregnant		
b. During my most recent pregnancy	□	
c. Since my new baby was born	🗆	

12 months before		During	Since	
Answer	Cases	Cases	Cases	
No	12	17	16	
Yes	7	1	2	

<u>Findings</u>: As with skip patterns throughout the questionnaire, respondents who answered 'no' in question 11 sometimes missed the skip instruction and answered this question by mistake. No one expressed confusion over the instruction, they simply did not read it.

Second, the timeframes were sometimes not accurately taken into account by respondents. As one respondent said, "It was a little difficult because you have to really read." This is evidence that, in general, respondents may not always read carefully.

The timeframes of 'during the 12 months before I got pregnant' and 'since my new baby was born' were less problematic than 'during my most recent pregnancy'. Several false negative answers were found among English language respondents, where they reported not using marijuana during pregnancy when, during probing, it was discovered that they did. Moreover, all false negative responses were committed by respondents who had not been intending to get pregnant or whose pregnancy was a surprise. Respondents who were not actively trying to get pregnant often did not discover they were pregnant until they were one to three months pregnant. As a result, those who were using marijuana did so when they did not know they were pregnant, and stopped as soon as they found out. In their mind, they did not use marijuana during pregnancy because they did not use it once they knew they were pregnant. For example, one respondent was asked why she answered 'no' once the interviewer established that she had smoked marijuana before she discovered she was pregnant. She said, "You know what...well, I would say being that it was just one month...but I guess if you're being really technical...". The interviewer asked what the respondent thought. She said, "I say no. Because it was just the first month." Another respondent echoed this sentiment and said of her smoking marijuana the three weeks she did not know she was pregnant, "Those [weeks] don't really count." In essence, because respondents did not know they were pregnant, they were not making a conscious decision to use marijuana during pregnancy. Clearly, among respondents who were not expecting to become pregnant, the important factor in interpreting the intent of the question rested on the notion that a woman made a conscious decision to use marijuana while pregnant.

# 13. During the 3 months before you got pregnant, how often did you use marijuana products in an average week?

- □ More than once a day
- □ Once a day
- □ 2-6 days a week
- □ 1 day a week or less
- □ I did not use marijuana products then

Answer	Cases
More than once a day	1
Once a day	1
2-6 days a week	1
1 day a week or less	4
I did not use marijuana produc	ets then 10

<u>Findings</u>: There were some mode issues for this question and others like it with similar response categories. In the phone version, few respondents listened to the entire list of options, often providing

an answer before the interviewer finished reading all the options. Others immediately replied with an answer upon hearing the question, without waiting to hear any of the response options. This slowed administration of the questionnaire. One respondent said, "I can't read the choices." and admitted it confused her. Often the responses had to be read more than once.

Second, there was some evidence of social desirability playing a role in respondents' answers, particularly for those who did not use marijuana on a regular basis. The correct answer would have been '1 day a week or less', but several respondents expressed dissatisfaction with that choice, suggesting that it implied more frequent use than was true for them. One respondent who smoked marijuana about once a month explained, "I would add another section that says, like, once a month. Because one day a week or less makes me feel like I'm a pot head or something."

# 14. During the *first 3 months of your pregnancy*, how often did you use marijuana products in an average week?

- □ More than once a day
- □ Once a day
- □ 2-6 days a week
- □ 1 day a week or less
- ☐ I did not use marijuana products then

Answer	Cases
More than once a day	0
Once a day	0
2-6 days a week	1
1 day a week or less	1
I did not use marijuana	15

<u>Findings</u>: As with skip patterns throughout the questionnaire, respondents who answered 'no' in question 11 sometimes missed the skip instruction and answered this question by mistake. No one expressed confusion over the instruction, they simply did not read it.

Several response errors were found among English language respondents, similar to question 12b. Respondents who had not been intending to get pregnant or whose pregnancy was a surprise tended to answer 'I did not use marijuana products then'. Respondents who were not actively trying to get pregnant often did not discover they were pregnant until they were one to three months pregnant. As a result, those who were using marijuana did so when they did not know they were pregnant, and stopped using it as soon as they did know. In their mind, they did not use marijuana during pregnancy because they did not use it once they knew they were pregnant. In essence, because respondents did not know they were pregnant, they were not making a conscious decision to use marijuana during pregnancy. The

important factor in interpreting the intent of the question rested on the notion that a woman made a conscious decision to use marijuana while pregnant.

Translation Note: 'Durante los primeros 3 meses (primer trimestre) de su embarazo' was a little confusing for some respondents. A better option may be: 'Durante los primeros 3 meses de su embarazo (primer trimestre).' The parentheses may also be unnecessary.

### 15. During the *first 3 months of your pregnancy*, how did you use marijuana?

- □ Smoke it (for example, in a joint, bong, pipe, or blunt)
- □ Eat it (for example, in brownies, cakes, cookies, or candy)
- □ Drink it (for example, in tea, cola, or alcohol)
- □ Vaporize it (for example, in an e-cigarette-like vaporizer device)
- □ Dab it (for example, using waxes or concentrates)
- □ Other Please tell us:

Answer	Cases
Smoke it (for example, in a joint, bong, pipe, or	2
Eat it (for example, in brownies, cakes, cookies,	0
Drink it (for example, in tea, cola, or alcohol)	0
Vaporize it (for example, in an e-cigarette-like	0
Dab it (for example, using waxes or concentrates)	0

<u>Findings</u>: This was not adequately tested because only two respondents answered in question 14 that they used marijuana during the first three months of pregnancy. Both answered 'smoke it' in this question. In fact, all respondents in the study who said they ever used marijuana, talked only of having smoked it (this was the dominant form of use) or, in two cases, also eaten it (e.g., in brownies).

# 16. During the *middle 3 months of your* pregnancy, how often did you use marijuana products in an average week?

- □ More than once a day
- □ Once a day
- □ 2-6 days a week
- □ 1 day a week or less
- □ I did not use marijuana

products then

Answer	Cases

More than once a day	0
Once a day	0
2-6 days a week	0
1 day a week or less	0
I did not use marijuana	16

<u>Findings</u>: All respondents chose 'I did not use marijuana products then'. No response error was reported and there was only one source of confusion over the timeframe. This was likely a mode effect for the phone version. One respondent heard only 'middle months of your pregnancy' and was not sure how to interpret that. She said, "Well that would be a problem right there, because what do you consider middle?" The interviewer asked what she thought. "I would think middle would be, like, five to seven months. Whatever the second trimester is, I guess. But some people might feel like four months is the middle of pregnancy." This respondent did not hear 'middle *three* months' when the question was read to her.

### 17. During the *middle 3 months of your pregnancy*, how did you use marijuana?

- □ Smoke it (for example, in a joint, bong, pipe, or blunt)
- □ Eat it (for example, in brownies, cakes, cookies, or candy)
- □ Drink it (for example, in tea, cola, or alcohol)
- □ Vaporize it (for example, in an e-cigarette-like vaporizer device)
- □ Dab it (for example, using waxes or concentrates)
- □ Other Please tell us:

Findings: This question was not tested because all respondents skipped out.

# 18. During the *last 3 months of your pregnancy*, how often did you use marijuana products in an average week?

- □ More than once a day
- □ Once a day
- □ 2-6 days a week
- □ 1 day a week or less
- □ I did not use marijuana

products then

Answer	Cases
More than once a day	0

Once a day	0
2-6 days a week	0
1 day a week or less	0
I did not use marijuana products then	16

<u>Findings</u>: All respondents chose 'I did not use marijuana products then'. No response error was reported and there was no source of confusion regarding timeframe.

### 19. During the *last 3 months of your pregnancy*, how did you use marijuana?

□ Smoke it (for example, in a joint, bong, pipe, or blunt)

□ Eat it (for example, in brownies, cakes, cookies, or candy)

- □ Drink it (for example, in tea, cola, or alcohol)
- □ Vaporize it (for example, in an e-cigarette-like vaporizer device)
- □ Dab it (for example, using waxes or concentrates)
- □ Other Please tell us:

<u>Findings</u>: This question was not tested because all respondents skipped out.

### 20. Why did you use marijuana products during pregnancy?

	NO YE
a. To relieve nausea	
b. To relieve vomiting	
c. To relieve stress or anxiety	
d. To relieve a chronic condition	
e. To relieve pain	
f. For fun or to relax	
g. Other	
Please tell us:	

<u>Findings</u>: There was not enough data to adequately evaluate this question. Almost all respondents reported not using marijuana during pregnancy. One respondent who reported that she did use marijuana during pregnancy chose 'other' and wrote that she did not know she was pregnant.

# 21. Since your new baby was born, how often do you use marijuana products in an average week?

- □ More than once a day
- □ Once a day
- □ 2-6 days a week
- □ 1 day a week or less
- □ I have not used marijuana products since my new baby was born

Answer	Cases
More than once a day	0
Once a day	0
2-6 days a week	1
1 day a week or less	2
I have not used marijuana products since my new baby was born	15

<u>Findings</u>: All respondents answered according to the correct timeframe and no error was found. As with previous items, some respondents answered this series of questions when they should have skipped, per the instruction back in question 11.

22. During any of your prenatal care visits, did a doctor, nurse, or other health care worker do any of the following things? For each item, check No if a health care worker did not do it, or Yes if they did.

	No Yes
a. Ask you if you were using marijuana	🗆 🗆
b. Prescribe marijuana for any reason	
c. Advise you not to use marijuana	🗆 🗆
d. Advise you not to breastfeed your baby	
while using marijuana	

	a	b	c	d
Answer	Cases	Cases	Cases	Cases
No	5	39	17	24
Yes	35	0	22	13

<u>Findings</u>: There were three primary issues for this question. First, some respondents conceptually combined all drugs into a single category. Respondents reported that these conversations took place on a very general level, which might include all illegal drugs as a single category, not just marijuana specifically. For example, one respondent said, "I remember that during my first visit the doctor asked me if I was using alcohol or drugs." Another said, "They only ask, 'Are you on drugs,' like cocaine, marijuana, hash or whatever the case may be." Similar responses included "They did ask me if I was doing drugs." or "They asked me, 'Do you do drugs?"" or "Yes. They worded it as, 'Do you use any drugs?"" One respondent summed it up this way, "It was just lumped in with everything else. Like with any other drug. It wasn't anything marijuana specific." Others remembered this conversation as

focused on what *not* to do in general during pregnancy, such as smoke cigarettes or drink too much caffeine or alcohol. One respondent said, "They go down the line of not smoking cigarettes, of not doing this, what not to eat." Respondents with this interpretation answered different ways. Thinking that marijuana counts as a drug or as something one should not do while pregnant, they said 'yes', even if marijuana was not specifically mentioned by the clinician. On the other hand, some respondents answered 'no' if marijuana was not specifically mentioned. Hence, to some respondents, the question was about whether the clinician talked about behaviors that might put a pregnancy at risk, while to other respondents it was specifically and only about marijuana.

A second issue was the manner in which respondents interpreted 'ask you' or 'advise you' in 22a, 22c, and 22d. Some respondents were not sure if this question was about an actual conversation. They reported providing this type of information on their intake questionnaires during prenatal visits, but that did not always translate into an actual conversation with a clinician. Many respondents answered 'yes' to this question even when the information was collected non-verbally. For example, one respondent referenced a questionnaire she completed at the beginning of her prenatal visit. "They do that screening when you first go in." Another remembered the same sort of activity and said, "It was on a questionnaire."

Third, Spanish language respondents sometimes had difficulty understanding what 'prenatal care visit' meant. The instructions before this question say 'cuidado prenatal' while the question reads 'control prenatal' (prenatal checkup). One respondent understood 'cuidado prenatal' (prenatal care) as birth control: "So as not to have babies..." She mentioned that she did not know what 'prenatal' meant. She understood 'visitas de control prenatal' (prenatal checkup visits) as "just going to the doctor" not necessarily while pregnant. Two other Spanish language respondents also understood it as 'just going to the doctor', they did not know what 'prenatal' meant.

23. During any of the following periods, did anyone smoke marijuana products inside your home, including you? For each time period, check No if no one smoked marijuana inside your home then, or Yes if someone did.

#### No Yes

a. In the 3 months before I got pregnant	_
b. During my most recent pregnancy	
c. Since my new baby was born	-

	Before	During	Since			
Answer	Cases	Cases	Cases			
No	32	35	36			
Yes	8	4	4			

<u>Findings</u>: Respondents did not demonstrate any error with the three timeframes in this question. They also did think about not only other people, but themselves as well. Only one respondent expressed some hesitation over how to interpret 'inside your home.' She said, "That's a tricky question. Because you

said – the question said – 'in my home'. On my balcony. I didn't smoke in my home. I could say yes and no at the same time." She chose to answer 'no'. Most others also had a strict interpretation of 'inside the home' and did not include smoking that occurred *at* the home, but outdoors.

24. During any of the following periods, did anyone keep edible marijuana products, such as brownies, cookies, or candy with THC, inside your home? For each time period, check No if no one kept marijuana inside your home then, or Yes if someone did.

No Yes	s
a. In the 3 months before I got pregnant $\Box$	
b. During my most recent pregnancy□	
c. Since my new baby was born	

	Before	During	Since
Answer	Cases	Cases	Cases
No	38	36	38
Yes	1	3	1

<u>Findings</u>: Respondents understood this concept – most were thinking of brownies or cookies. No timeframe errors were committed. However, one respondent reported a false negative because the language of 'keep...inside your home.' She said, "When they say 'keep', who keeps this stuff in their home? It's not like we store it." This raises the issue of what, exactly, the question is trying to measure. Respondents who reported using such products did so episodically and immediately – it was not something they had in their house on a regular basis. The phrasing, 'keep inside your home' can imply a regular pattern of storage.

# 25. How much do you think pregnant women harm their own health when they use marijuana?

- □ No harm
- □ Slight harm
- □ Moderate harm
- □ Great harm

Answer	Cases
No harm	2
Slight harm	5
Moderate harm	8

Great harm	24

Findings: See summary after question 26.

26. How much do you think pregnant women harm their unborn baby's health when they use marijuana during pregnancy?

- □ No harm
- □ Slight harm
- □ Moderate harm
- □ Great harm

Answer	Cases
No harm	0
Slight harm	2
Moderate harm	8
Great harm	29

<u>Findings for 25 and 26</u>: Respondents answered both attitude questions similarly. Often (but not always) they expressed greater harm to the baby than the mother because of fetal development, giving rationales for the baby such as, "Because the baby's system is not as strong as the mother's." or "They're barely made of any cells...they're just developing." The mother, on the other hand, is fully developed and, therefore, more resilient. One respondent explained her answers of 'slight harm' to the mother but 'moderate harm' to the baby, saying,

Because I still don't really see the huge effect that marijuana has had on people that smoke. Everyone that I know, I've never seen anything crazy happen, even with health. And I know people much older than myself that are smoking. I just don't know that there's any real harm to it. Other than getting hungry!

While many respondents thought great harm could come to the baby, many explained that they did not know the specific detriments that may result. For example, one respondent said, "For the unborn baby I would think brain development and things like that it would affect. I don't know the research behind it, but I can just imagine." Another respondent also expressed uncertainty with details, "I don't know exactly what it can cause, but I know it's harmful." In a similar vein, another respondent said, "They don't explain when you go to the doctor how it's harming the baby. Is the baby going to be autistic? Or something wrong with the baby's brain?" Other respondents were able to speculate:

For the mother, it's a drug and it affects all your organs, especially your brain – your ability to think. For the baby it's great harm because the baby is developing in the womb. And if you take a very strong drug like marijuana, the baby can be born with all kinds of problems. Brain problems...maybe like Down Syndrome or something like that.

One note about question ordering. Because question 25 references a pregnant woman, a couple respondents were also thinking of the baby when answering, making question 26 a bit redundant. For example, one respondent answered 'great harm' to question 25 but was thinking more about the baby than the mother. In explaining her rationale, she said, "I guess I was told that it would harm the baby – any type of drug." Asking about the unborn baby first and then the woman might do a better job of conceptually separating the two.

27. During the *month before* you got pregnant, did you take or use any of the following drugs for any reason? Your answers are strictly confidential. For each item, check **No** if you did not use it in the month before your pregnancy, or **Yes** if did.

No Yes
a. Over-the-counter pain relievers such as
aspirin, Tylenol®, Advil®, or Aleve® □
b. Prescription pain relievers such as
hydrocodone (Vicodin®), oxycodone
(Percocet®), or codeine
c. Adderall®, Ritalin®, or another stimulant
d. Marijuana or hash
e. Synthetic marijuana (K2, Spice)
f. Methadone, naloxone, subutex, or
Suboxone®
g. Heroin (smack, junk, Black Tar, <i>Chiva</i> )□
h. Amphetamines (uppers, speed, crystal
meth, crank, ice, agua)
i. Cocaine (crack, rock, coke, blow, snow,
nieve)
j. Tranquilizers (downers, ludes)
k. Hallucinogens (LSD/acid, PCP/angel
dust, Ecstasy, Molly, mushrooms, bath
salts)

	a	b	С	d	e	F	g	h	i	j	k
Answer	Cases										
No	13	37	40	35	40	40	40	40	40	40	40
Yes	27	3	0	5	0	0	0	0	0	0	0

<u>Findings</u>: While many respondents answered 'yes' to the first item (over-the-counter pain relievers or OTCs), fewer answered 'yes' to b (prescription pain relievers) and d (marijuana) and none answered 'yes' for the other drugs on the list. Respondents tended to know what heroin and cocaine were, but had not heard of the other names included for these drugs. This was especially true among the Spanish language respondents. As a result, the extensive list of examples was probably unnecessary for those items.

Most respondents reported having taken OTC pain relievers for things like headaches and body aches. Only one respondent mistakenly thought of prescription medication when she answered 'yes' to item a.

The central problem with this question was the timeframe of one month before pregnancy. This was the only question that used this timeframe and many respondents missed it. They tended to think about what they took during pregnancy instead. The following are examples:

When I was about six months pregnant I was getting headaches and used Tylenol.

I have had pain, like a lot of headaches. And I have asked my doctor if I can use Tylenol and it's the only thing that's okay to take. And it's the only thing I took while pregnant.

Tylenol is a drug? I would not think so because the doctors prescribe it. And when you are pregnant they tell you that you can take Tylenol, acetaminophen.

One respondent who missed the timeframe for item b reported 'yes' because she was given prescription pain killers when she was hospitalized during her fifth month of pregnancy. She said:

I was hospitalized, so they put me on these big drugs. But afterwards they didn't, so I don't know how to answer that question...just because I didn't use them at home...but I did use them at some point [in the hospital].

28. During your most recent pregnancy, did you use prescription pain relievers such as Vicodin®, Percocet® or OxyContin®, Demerol® or Hydrocodone? Please do not include "over thecounter" pain relievers such as aspirin, Tylenol®, Advil®, or Aleve®.

□ No
□ Yes, I used them the way my doctor directed me to use them
□ Yes, I used them but not how my doctor directed (e.g., without a prescription of my own, in greater amounts or longer than I was told to take them)

Answer	Cases
No	26
Yes, I used them the way my doctor directed me to use them	3
Yes, I used them but not how my doctor directed (e.g., without a prescription of my own, in greater amounts or longer than I was told to take them)	0

<u>Findings</u>: Respondents took into account the correct timeframe but often were not familiar with the specific drug names. However, no response error was detected. Only one person had difficulty with the

categories because they were not mutually exclusive for her. She had what she described as an addiction to prescription pain killers that was prompted by having undergone multiple surgeries over the course of several years. She chose both 'yes' categories because she took the drugs as prescribed at first, but eventually took them more often than prescribed. She explained the situation around her most recent pregnancy:

I had two major surgeries. I had a C-section and I had my gall bladder taken out. So most of the time I was just taking the pills just because I wanted to take them. I think because I got addicted. And most of the time the doctor just gave these to me. I'm still taking Tramadol.

A note on mode: As mentioned earlier, this question was very cumbersome and difficult to read aloud in the phone version. For example, interviewers frequently struggled pronouncing the names of the specific drugs. Respondents heard one aspect of the question (such as 'prescription pain reliever') and answered on that basis.

# 29. During your most recent pregnancy, did you use heroin, cocaine, amphetamines, or barbiturates such as phenobarbital?

 $\; \square \; No$ 

□ Yes

<u>Findings</u>: Only one respondent reported 'yes' to this question. Most answered 'no'. All thought of the correct timeframe and knew what cocaine was.

A note on mode: As mentioned earlier, this question was very cumbersome and difficult to read aloud in the phone version. For example, interviewers frequently struggled pronouncing the names of the specific drugs. All respondents were familiar with heroin and cocaine and most answered on that basis.

# 30. During *your most recent* pregnancy, did you use prescription antidepressants or selective serotonin reuptake inhibitors (SSRIs) such as Sarafem®, Zoloft®, or Lexapro®?

 $\sqcap Nc$ 

 $\hfill \Box$  Yes, I used them the way my doctor directed me to use them

□ Yes, I used them but not how my doctor directed (e.g., without a prescription of my own, in greater amounts or longer than I was told to take them)

Answer	Cases
No	27
Yes, I used them the way my doctor directed me to use them	1
Yes, I used them but not how my doctor directed (e.g., without a prescription of my own, in greater amounts or longer than I was told to take them)	2

<u>Findings</u>: A few respondents answered yes to this question, but most answered 'no'. All thought of the correct timeframe. Even though many had not heard of these drugs, no response error was found.

A note on mode: As mentioned earlier, this question was very cumbersome and difficult to read aloud in the phone version. For example, interviewers frequently struggled pronouncing the names of the specific drugs. Respondents heard one aspect of the question (such as 'antidepressants') and answered on that basis.

31. During your most recent pregnancy, did you use any prescription benzodiazepines such as diazepam or chlordiazepoxide?
□ No
☐ Yes, I used them the way my doctor directed
me to use them
☐ Yes, I used them but not how my doctor
directed (e.g., without a prescription of my
own, in greater amounts or longer than I was
told to take them)

<u>Findings</u>: All respondents answered 'no' to this question. All thought of the correct timeframe. Even though some had not heard of these drugs, no response error was found.

A note on mode: As mentioned earlier, this question was very cumbersome and difficult to read aloud in the phone version. For example, interviewers frequently struggled pronouncing the names of the specific drugs.

32. During any of your prenatal care visits, did a
doctor, nurse, or other health care worker
refer you to treatment because of drug use
(prescribed or non-prescribed drugs)?
□ No
□ Yes
□ I didn't go for prenatal care

<u>Findings</u>: Almost all respondents skipped out of this question so it could not be adequately tested.

33. After your baby was born, did a doctor, nurse, or other healthcare worker tell you that your baby had drug withdrawal or neonatal abstinence syndrome?

□ No
□ Yes

<u>Findings</u>: Almost all respondents skipped out of this question so it could not be adequately tested.

34. During your most recent pregnancy, how often did you eat largemouth bass, tuna, shark, king mackerel or swordfish?

□ 3 or more times a week
□ 1 to 2 times a week
□ 1 to 3 times a month

□ Less than once a month
 □ I didn't eat those fish during my pregnancy

Answer	Cases
3 or more times a week	0
1 to 2 times a week	2
1 to 3 times a month	7
Less than once a month	8
I didn't eat those fish during my pregnancy	13

<u>Findings</u>: Respondents were thinking of the correct timeframe when answering this question, and many thought of canned tuna or ahi tuna. However, for some the question was about the safety of eating raw fish – not mercury levels in fish – so they did not limit their thinking to the examples given in the question. As one respondent said, "I think I stayed away from everything raw." Another respondent explained how her doctor instructed her to cook everything thoroughly because shell fish can contain bacteria harmful to the baby.

Another issue emerged among the Spanish language respondents. Many were not familiar with some of the examples. One respondent said, "At first I did not understand it, but then I understood these were fish." The most commonly misunderstood examples were largemouth bass, king mackerel, and swordfish.

# 35. Where did you get largemouth bass, tuna, shark, king mackerel or swordfish that you ate during your pregnancy?

- □ From the grocery store
- □ From a fish market or farmer's market
- □ From a restaurant
- $\hfill\Box$  Caught by you or someone else from a local river, stream, lake, or pond
- □ Caught by you or someone else from one of the Great Lakes
- □ Other Please tell us:

Answer	Cases
From the grocery store	14
From a fish market or farmer's market	1
From a restaurant	6

Caught by you or someone else from a local river, stream, lake, or pond	0
Caught by you or someone else from one of the Great Lakes	0
Other> Please tell us:	0

<u>Findings</u>: Respondents had no difficulty choosing from among the options. Grocery store was by far the most common choice, followed by restaurant. Only one person who chose grocery store was unsure of her answer. She was not sure whether Walmart counted as a grocery store – "I think they call it a 'mass merchandizer, something like that." – but decided that the 'grocery store' option was the best choice.

36. During your most recent pregnancy, did you use any of the following products one or more times per week? For each item, check No if you did not use it one or more times per week, or Yes if you did.

n you ara.	
	No Yes
a. Cockroach or other bug sprays or baits	
b. Insect repellents for personal use	
c. Rat poison or other rodent poisons	
d. Weed killers	
e. Flea and tick sprays, powders, or pet	
collars	

	a	b	c	d	e
Answer	Cases	Cases	Cases	Cases	Cases
No	32	29	40	40	38
Yes	6	10	0	0	2

<u>Findings</u>: Respondents generally were familiar with the items on this list. However, several issues were found that caused difficulty or in some cases response error.

First, the timeframe of 'during your most recent pregnancy' was taken two ways. Some respondents were thinking of whether they used the product one or more times a week during their *entire* pregnancy while others were thinking of only some portion of their pregnancy. For example, respondents who answered 'yes' to using bug sprays only did so for a limited amount of time. One respondent went on a retreat in the mountains when she was three or four months pregnant and used bug spray frequently, but only during her stay there. Another respondent moved in the middle of pregnancy into a new home that had wasp nests on the property. She used a spray to eradicate the nests, but this was not over the course of her entire pregnancy, it was only in the last month or two.

Second, although respondents were thinking of the correct timeframe, 'during your most recent pregnancy,' they did not always think of the correct frequency of use, 'one or more times per week.' Rather, they would sometimes report *any* frequency of use during pregnancy. For example, one respondent said 'yes' to using bug repellent but during probing explained, "I didn't use it very often." Others reported similar false positive answers (especially for bug sprays and insect repellent), explaining that they used such items only once a month or once every couple months over the course of their pregnancy.

Third, respondents had varying definitions of what constitutes 'use'. Many respondent were thinking that they, themselves, were to have used/applied the product (particularly weed killers and flea treatments). One respondent expressed confusion over weed killers. She asked, "Do I specifically have to spray it on the ground? Or did somebody treat my yard?" She did not apply the chemical (her husband did) but she understood that she was still exposed to it because she was in her yard. She decided to interpret 'use' literally and answered 'no'. However, others interpreted the question as asking more broadly whether they were *exposed* to these chemical and decided to answer 'yes'. One respondent thought about the flea collar her dog wears. While the dog gets a new flea collar only every few months, she still thought of herself as exposed to those chemicals every day. Others with the same experience answered 'no' if the collar was not replaced once or more a week or if they, themselves, did not apply the treatment (i.e., put the collar on the dog). In sum, respondents with similar experiences provided different answers depending on whether they interpreted the question as broadly asking about exposure to a chemical or more narrowly about literally handling a product.

# 37. During your most recent pregnancy, did you use or have contact with any of the following things on a daily basis (every day)? For each item, check No if you did not use it every day, or Yes if you did.

i es il you did.	
	No Yes
a. Strong degreasers such as oven cleaner	
or heavy duty degreaser	
b. Furniture or shoe polish	
c. Bleach products without good	
ventilation	🗆 🗆
d. Clothes that were freshly dry-cleaned	
e. Air fresheners, plug-ins or incense	
f. Strong smelling perfume or deodorant	
g. Strong smelling nail polish	

	a	b	С	d	e	f	g
Answer	Cases						
No	33	37	33	29	17	25	29
Yes	7	3	7	9	23	15	11

<u>Findings</u>: This question had patterns of interpretation similar to the previous. In the previous question, the word 'use' was interpreted as either literally handling a product or as simply having exposure to the

chemicals in the product. Similar interpretations occurred with this question, but the pattern was more pronounced because of the phrase 'have contact with'. For example, one respondent answered 'yes' to all items on this list. When asked to explain, she said that when she was pregnant, "I did clean the apartment a lot." When asked how often she said, "I didn't clean every day. But I was exposed to all that stuff, at least at one point." Clearly her interpretation was that the question was more about exposure – any exposure – than literal use.

Other respondents also answered 'yes' on the basis of whether they *ever* used these products during pregnancy because they simply missed the reference to 'daily' use. This was especially true of oven cleaner, bleach, or dry-cleaned clothes. Respondents who answered 'yes' often revealed during probing that they did not use (or have contact with) these products every day. Many gave frequencies such as one or two times a week or month.

Item d (dry-cleaned clothes) created some confusion as well, particularly among the Spanish language respondents. One respondent commented, "I really do not know. How can you dry-wash clothes?" The source of confusion was likely the translation. Respondents understood it by saying 'clothes cleaned at the 'tintoreria' (the latter term is a dry cleaners store, except the word does not include a description of how the clothes are cleaned); respondents did not recognize the terminology used in the question. Others were unsure whether the question was asking whether they worked at a dry-cleaners or simply took their clothes there as customers.

# 38. During *your most recent* pregnancy, on average, how often did you eat food that was microwaved in a plastic container?

More than once a day

%. Once a day

%. 2 to 6 times a week

- □ Once a week
- □ Less than once a week
- □ Never

Answer	Cases
More than once a day	2
Once a day	8
2 to 6 times a week	8
Once a week	6
Less than once a week	12
Never	3

<u>Findings</u>: Respondents had no difficulty with this question, but there were two different scenarios that came to respondents' minds. Some respondents were thinking of heating up leftovers in plastic storage

containers, others thought of heating pre-packaged meals (such as TV dinners), and a few were thinking of both. No one had difficulty choosing a category and no response error was found.

### 39. Are the bottles that you use to feed your new baby BPA free?

. 1	N	0
	·	v

- □ Yes, sometimes
- □ Yes, all the time
- □ I don't know
- $\ \square$  I don't use plastic bottles when feeding my baby

Answer	Cases
No	5
Yes, sometimes	2
Yes, all the time	18
I don't know	12
I don't use plastic bottles when feeding my baby	1

Findings: The main difficulty with this question had to do with the level of knowledge respondents had of BPA and baby bottles. Many had very little. Respondents who had little knowledge or who never thought about it gave different answers. Some respondents answered 'don't know'. In explaining her answer, one respondent said, "I know I've seen this, but I'm just not enough into it to say yeah or no. I probably do, but I'm not positive." Several respondent said they had heard of BPA but did not know what it stood for or what it was. On the other hand, some respondents chose 'no' as a proxy for 'don't know'. For example, one respondent answered 'no' but during probing said, "Which I really don't know. It's not something I look for when I go shopping." On the other end of the spectrum, some respondents who did not know answered 'yes, all the time' because they assumed all new bottles are made without BPA. One respondent said, "I don't even know. But I'm assuming because they are brand new bottles." However, some respondents understood this chiefly as a question about the use of plastic bottles. One respondent said she had never heard of BPA, but answered 'yes, all the time' simply because she used plastic bottles.

One problem was found for respondents who used only glass bottles or no bottles at all. The categories were not mutually exclusive or exhaustive for them. One respondent used only glass bottles. Rather than choosing 'I don't use plastic bottles', she chose 'yes, all the time' because glass bottles by definition do not have BPA. Another respondent who breastfed exclusively and didn't own any bottles answered 'no'. While 'I don't use plastic bottles' may have been the better answer for her, there was no category that fit her answer exactly.

### 40. Was the house or apartment you live in now built before 1978?

□ No□ Yes

Answer	Cases
No	15
Yes	14

<u>Findings</u>: There were no conceptual misunderstandings or variety in interpretations of this question, but many respondents simply did not know the answer. This was especially true among renters. Sometimes this was not a problem because the building was very old. One respondent who did not know the age of the building but answered 'yes' anyway said, "I am not sure in what year it was built. But I do know it is old." Others would answer 'no' but had the same rationale: "I don't believe they're that old." Or "I want to say 1982...I know it's in the 80's." However, some respondents could not offer a guess and would leave the question blank because there was no option for 'don't know'. In explaining why she left the item blank, one respondent said she was not very good at guessing the age of buildings, so she didn't try to. Others left the question blank for similar reasons.

### 41. Has the house or apartment you live in now been tested for lead paint?

 $\; \square \; No$ 

□ Yes

□ I don't know

Answer	Cases
No	12
Yes	7
I don't know	4

<u>Findings</u>: This question had a 'don't know' option, so respondents who lacked knowledge tended to choose that response. Many respondents took the question as asking whether their house or apartment has been tested since they lived there – not whether it was *ever* tested. One respondent answered 'no' and said, "I based it on the time I have lived here. They have not done any tests." Another also answered 'no' because it has not been tested since she's lived there. She said, "Maybe in the past, but we've never had it tested." Similarly, another respondent was basing her answer of 'no' on her personal experience. She said, "Myself, I don't know that they have done it. But it's possible."

### 42. Does the house or apartment you live in now have a working carbon monoxide detector?

□ No

¬ Yes

Answer	Cases
No	5
Yes	29

<u>Findings</u>: This was another question to which respondents often did not know the answer. Without the option of a 'don't know' response, some respondents chose to leave the item blank. One respondent said, "I don't even know. I know I got a smoke detector. But that's it." Another said, "I have no idea what it is. I'm hoping they have it because it's a new house and they have standards now for buildings."

# 43. Has your home's air been tested for the presence of radon, a gas that is found in the air in some homes?

- $\square$  No
- □ Yes
- □ I don't know

Answer	Cases
No	23
Yes	5
I don't know	12

<u>Findings</u>: This item offered a 'don't know' option and 12 respondents chose it. There were two reasons behind the choice of 'I don't know'. Some respondents knew what radon was, but did not know whether their home had been tested for it. Other respondents chose this option because they did not know what radon was. However, answers were not consistent among those respondents who did not know what radon was. Some would answer 'no' instead of 'I don't know'. During probing one person said, "I should've said 'I don't know' because I've never heard of it." Another who answered 'no' said, "I really don't know. I don't think so."

# 44. During any of your prenatal care visits, did a doctor, nurse, or other health care worker talk with you about any of the things listed below? Please count only discussions, not reading materials or videos. For each item, check **No** if no one talked with you about it, or **Yes** if someone did.

	No Yes
a. How eating fish with high levels of	
mercury during pregnancy could affect	
my baby	
b. How me being exposed to lead could	
affect my baby	
c. Medicines that are safe to take during	

pregnancy □ □
d. How using pesticides, which are
chemicals to kill insects, rodents or
weeds during pregnancy, could affect
my baby $\square$
e. How using water bottles or other bottles
made of polycarbonate plastic (BPA,
recycle #7) during pregnancy could
affect my baby

	a	b	c	d	e
Answer	Cases	Cases	Cases	Cases	Cases
No	19	25	7	30	39
Yes	21	15	32	10	0

<u>Findings</u>: Respondents had different interpretations regarding the intent of this question. Despite the instruction at the end of the question, some respondents did not base their answer on an actual discussion, but were including information that was conveyed to them nonverbally. For example, some respondents referred to "handouts" or "lists" with information regarding what they should avoid during pregnancy and what was safe. One respondent said, "They gave me a booklet – a special booklet for maternity. They showed me the pages with the medicines and symptoms – for example, if I have a headache, what is safe to take." A couple other respondents answered 'yes' because they were shown an educational video while waiting to see the doctor. To this group of respondents, the question was about whether (not how) the information was conveyed to them.

Relatedly, because the question does not specify about which pregnancy to think, some respondents were not thinking of their most recent pregnancy when answering. To them the question was about whether a clinician *ever* conveyed this information to them during any prenatal visits. One respondent answered 'yes' because her doctor did cover these topics, just not during her most recent pregnancy. "I have had that talk about all those things, but not with this pregnancy."

Additionally, some respondents answered based on questions *they* had and topics *they* initiated with their doctor, not the other way around. The question does not specify but does imply that it is referring to conversations initiated by the clinician rather than the patient. For example, one respondent answered 'no' to all items and explained, "They told me about Tylenol because I asked them. But for them to tell me voluntarily what I can take or not, no." Another person described a similar experience but chose to answer 'yes'. "Because of the back pain I have I also asked him if I could take Tylenol." One respondent called the doctor's office to see what was safe to take for pain (she thought she was passing a kidney stone). Not only did she initiate asking about OTC drug safety, she did not do so during a prenatal care visit. She nevertheless decided to answer 'yes' because the information was conveyed. When and how it was conveyed or who initiated it was beside the point.

**45.** During *your most recent* pregnancy, did you do any of the following things? For each thing,

check No if you did not do it or Yes if you did.

NO TES
a. Eat fish with high levels of mercury □
b. Come in contact with fumes from fresh
paint 🗆 🗆
c. Come in contact with lead paint dust
from house remodeling
d. Eat food microwaved in plastic
containers
e. Take medicines that are not
recommended by my doctor
f. Drink out of plastic bottles like those
made of polycarbonate (BPA,
recycle #7)

	a	b	c	d	e	f
Answer	Cases	Cases	Cases	Cases	Cases	Cases
No	32	30	36	8	31	13
Yes	5	9	2	31	8	17

<u>Findings</u>: Only items a (fish with mercury) and f (plastic bottles with BPA) caused difficulties for respondents. Respondents were not always aware of dangers surrounding mercury in fish and they did not know which fish contained high levels. Two respondents answered 'yes' because they ate salmon. But a third respondent asked, "Does salmon have high levels of mercury?" Examples of respondents who answered 'no' when they really did not know include:

I don't know the levels of mercury in fish.

I put 'no' because really I don't know what fish have high levels of mercury.

I actually don't know if fish has mercury or not.

I don't know which fish has really high [mercury].

I don't think about fish that way. I thought, okay, fish is healthy. It has protein. So I tried to eat fish to be healthy. I never thought about how much mercury the fish has.

Some respondents had difficulty with the last item as well. Some left it blank because they were confused or did not know. One respondent explained, "I don't' know what BPA is. I don't know if I'm drinking with it or without it." Another who left it blank said, "I drank water in plastic bottles, but I never heard of polycarbonate."

Other respondents interpreted this question as asking whether they drank out of plastic bottles at all, irrespective of BPA. Many answered 'yes' on this basis. One person explained, "I'm thinking the regular water bottles that you get in the grocery store." Another said, "I thought they were asking about

plastic bottles – you know, bottled water. I would drink it all the time, bottled water." Several other respondents also answered 'yes' similarly thinking of bottled water they bought by the case without being aware of BPA.

# 46. Was your doctor, nurse, or other health care provider able to answer any questions about environmental exposures that you had during your pregnancy?

- □. No
- □. Yes
- □. I didn't have any concerns about environmental exposures

Answer	Cases
No	5
Yes	10
I didn't have any concerns about environmental exposures	23

<u>Findings</u>: Most respondents interpreted this question as asking about outdoor pollution. When asked for examples of what they were thinking, they gave answers such as:

Too much sun...swimming in dirty water...being outside breathing in smoke.

Things out in the street. Buses, cars...the fumes and stuff. Things like that.

Maybe if I lived next to some kind of factory.

I'm thinking of gases, smoke, harmful chemical. Things of that sort.

Things that you find in the environment, like gasoline smells

Additionally, the list of response options is not mutually exhaustive. One respondent chose 'no' but this was not accurate. She did have questions, but did not ask her doctor. She researched it herself online. "If I needed to know, I would just end up looking it up myself. So I guess I just didn't have questions for them. Not that I didn't have questions at all."